# Caregivers' Role in Caring for Children with Cleft Lip-Palate in Mobile Speech Camp

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***Background:*** *Clefts lip and palate (CLP) are among the common orofacial congenital malformations. The treatment needs long-term multidisciplinary team approach. CLP impact both children's physical and psychological aspects as well as caregivers' burden. Children with CLP face challenges such as abnormal facial configuration, swallowing disorders, speech and language defects, hearing problems and dental abnormalities. Parents or caregivers play an important role in caring.*
***Objective:*** *To examine caregivers' role in caring for children with CLP who visited a mobile speech unit in Chiang Kham Hospital, Phayao, Thailand.*
***Material and Method:*** *This study was qualitative research. Caregivers of the children with CLP, who attended mobile speech camp at Chiang Kham Hospital, Phayao were recruited. Data were collected using Tawanchai Quality of Life, Thai Cleft Quality of Life Questionnaire for children with CLP and in-depth interviews. Data were analyzed using Leonard Method.*
***Results:*** *The majority (77.80 %) of the CLP children were cared by their mothers. Most caregivers of the children with CLP were depended on agriculture income. Their major concerns for caring the child with cleft lip and palate were a search for: 1) Treatment (70.40%): the most common information that caregivers needed was treatment; 2) Development stimulation (70.20%), especially speech and language therapy; and 3) General care (52.60%): prevention of infection; lower respiratory infection and otitis media, as well as providing effective oral intake and sucking and good nutrition, respectively.*
***Conclusion:*** *Mothers had a major role for caring the children with CLP. The most concern for caring was searching for treatment, followed by development stimulation, particularly speech services. The information was useful for treatment planning and providing counseling for new caregivers.*

***Keywords:*** *Caregiver role, Parental need, Cleft lip and palate, Speech services*

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Clefts lip and palate (CLP) are neonatal anomalies that develop during the 1st trimester of pregnancy and due to failure in fusion process of the lip and/or palate tissues(1,2). Cleft lip (CL) is opening of the upper lip and can extend to base of the nostril whilst the cleft palate (CP) is opening of the roof of mouth. Incidence and prevalence of CLP varied with ethnicity, region and socioeconomic status. Average incidence rate of CLP is 0.11-2.49 for every 1,000 live births(3). Asia has higher incidence than Europe approximately 1.5-2 times(4). In Thailand, prevalence rate ranges 0.58-2.49 per 1,000 live births(5), particularly in northern Thailand, which the prevalence rate is 1.50 cases per every 1,000 live births(6).

Children with CLP face various challenges, including psychological, physical, social and economical issues that negatively affect both the children and their families. Physical problems include abnormalities of facial configuration, teeth, swallowing difficulties, delayed development, especially hearing speech, and language problems(7). The long-term management requires multidisciplinary team commitments from birth until the age of 21. Average cost of treatment is approximately 80,000-100,000 Baht (US$ 2,286-2,857), often exclusive of transportation, food and other living expenses(3).

Following surgical repair of lip and palate, most of the children still have major speech disorders from compensatory mechanism of velopharyngeal insufficiency (VPI). This impacted in delayed speech and language development 92% (49% of them needed speech therapy)(8,9), articulation disorders 51-63%(9), voice abnormality 12.5-25%(10-12), and resonance disorders 20-30%(13-15). Although, study of quality of life (QoL) in children with CLP's families revealed that

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there were high levels of QoL, the children still suffered anxiety of self-concept and image(16). A previous study showed that caregivers lacked knowledge in CLP, treatment, caring of children after surgery(17). Home visits were one of the management processes that relieved anxiety about treatment, self-concept, image and social adaptation(18).

Parents and caregivers of the children with CLP have an important role for caring and helping the children to cope with many difficulties and serve the children's needs. Health care providers should recognize parental or caregiver roles in caring for children with CLP and helping them to stimulate the children to have normal milestones, good health and good QoL and lead to living a near normal life in society.

## Objective

This study aimed to examine caregivers' role in caring for the child with CLP in Chiang Kham Hospital, Chiang Kham, Phayao, Thailand.

## Material and Method

### *Study design*

This study was qualitative research and the protocol was approved by the Khon Kaen University Ethics Committee for Human Research (Project No. HE581373).

### *Participants*

Nine caregivers of the children with CLP, who enrolled in the Mobile Speech Camp in Chiang Kham Hospital, Chiang Kham, Phayao in June 2015.

Tawanchai Quality of Life, Thai cleft Quality of Life Questionnaires for children with CLP(19) and in-depth interviews were used to collect data from caregivers who attended the Mobile Speech Camp, in Chiang Kham Hospital, Chiang Kham, Phayao.

The participant's general information, including gender, age, occupation, education level and family income were included. Tawanchai Quality of Life Questionnaire was used for eliciting information about family needs, included: 1) Needs of a nursing and medical education management plan; 2) Medical and related services; and 3) Satisfaction with the quality of care. The 20-question Thai Cleft QoL was also used for collecting. Each item of these questionnaires was rated as a Likert-type rating score from 1 to 5.

Data collection was performed after caregivers' verbal permission. For in-depth interviews, information was elicited by asking seven open-ended questions as follows:

1) What were the health problems at birth of your children with CLP?

2) Who was the main caregiver for the children with CLP?

3) What did you do for support or care for your children?

4) How did you stimulate CLP's development, including growth, speech and language, social and cognition?

5) How did you promote health of the children with CLP?

6) What did you do with children with CLP when they displayed inappropriate behavior such as aggression, regression and tantrum?

7) Were there the different roles between caregivers for normal children and children with CLP? How were they different? What did you need in caring for the children? From whom did you need help or support?

Each session of data collection took 15-30 minutes. Audio recorder (Sony ICD-UX80) was used for recording and the transcription was later performed.

Descriptive analysis was used for general characteristics, and the caregivers' needs were analyzed using mean and standard deviation. Content analysis was used for in-depth interviewing data based on Leonard's Method.

## Results

Table 1 displays the caregivers' demographic data. Most caregivers were mothers who were agriculturists. Average income widely varied from low to middle economic status.

Caregivers' needs were summarized based on mean ($\bar{x}$) and standard deviation (SD) (Table 2).

The majority of caregivers needed to know information in speech training, for nursing and medical education management plans, and needed a referral from their local health services to a special center, and were satisfied that the children were satisfied in themselves.

The Thai QoL scores could be grouped into the following aspects: majority of caregivers had to work more to compensate health expenses for children with CLP in economic aspect (items 1-4); had less time to take care for other children in family aspect (items 5-7); most family members were very supportive in the psychological support aspect (items 8-14); there was no problem in social aspect (items 15-16); and in physical aspect (items17-20).

For content analysis, the present study found

**Table 1.** Parents and caregivers' demographic

| Variables | Number (%) |
|---|---|
| Gender | |
| Males | 2 (22.2) |
| Females | 7 (77.8) |
| Status | |
| Mother | 7 (77.8) |
| Father | 1 (11.1) |
| Grandfather & Grandmother | 1 (11.1) |
| Age (years) | |
| 18-25 | - |
| 26-35 | 4 (44.5) |
| 36-45 | 3 (33.3) |
| 46-55 | 2 (22.2) |
| Occupation | |
| Employee | 3 (33.3) |
| Agriculture | 4 (44.5) |
| Merchant | 2 (22.2) |
| Education | |
| Illiterate | - |
| Primary school | 2 (22.2) |
| Secondary school | 2 (22.2) |
| Certificate | - |
| Bachelor degree | 5 (55.6) |
| Income (Baht) | |
| Mean (SD) | 15,667 |
| Median (minimum: maximum) | 9,000:30,000 |

that the parents and caregiver looked for information related to CLP as follows:

1) Treatment: most of the caregivers searched for information of treatment (72.40%). They searched for how to treat their children as soon as possible when they knew that their children had CLP. Examples of speech were "Where can we get the treatment?" or "How far can we get the treatment?".

2) Developmental promotion: the caregivers were seeking for knowledge of development stimulation (70.20%), with major concern in looking for speech services. They wanted to know techniques or strategies for speech correction at home. Samples of their expressions were "My child has clearer speech now; mom usually teaches him/her every time when he/she speaks unclearly".

3) General caring: they needed to know information for preventing wound infection after surgery (52.60%), particularly lower respiratory tract infection and ear infection. Major concerns about general care were feeding and developmental promotion. An example of their expression, "What kind of food child requires?; we will find for them to promote good health for him/her.

Though caregivers were satisfied with surgical results, they were having minor issues regarding the facial configuration that was understood from their speech "Face is better, however, nose looks flat, I would like to take my child to consult a physician to correct the tip of the nose".

Regarding negative impact on families, there was no negative effect after children with CLP received treatment based on standard protocol. They were happy and had no anxiety and could live a normal, daily life like other people. They felt that family's member were generous and helped each other. An example of their speech was, "We do everything that we can, we have normal activities and can travel anywhere that we need in normal situation".

## Discussion

The majority of the caregivers were mothers of the children with CLP. They firstly searched for information about nursing and a medical education management plan (mean = 3.63, SD = 0.55) (Table 2). This agreed with most needs in seeking knowledge for medical services, a referral system and a health care unit where they could get services for their children (mean = 3.67, SD = 1.32; mean = 3.78, SD = 1.24, respectively) (Table 3). As we know, children with CLP normally need multidisciplinary approaches and long-term treatment from birth to 21 years of age; most caregivers might get high level of fear and anxiety when taking care of their children. Therefore, they search for correction of facial configuration as soon as possible and hope that their children will attain normal or near normal faces that is consistent with the previous studies(20,21). It also supports Orem's Theory(21) in parents and caregivers' seeking information for sick children with the following three modalities: 1) General care in feeding, drinking, air taking, relaxation, exercise, excretion, prevention of infection and accident; 2) Promotion for normal development, including speech and language, physical, social and cognitive developments; and 3) Special needs in caring for health abnormality in searching for treatment and nursing care following a standard management plan. These findings were similar to caring for children with heart disease and confirm that parents and caregivers need health care knowledge from physicians in caring for their children(22).

This present study showed that the caregivers needed to know about programs and planning for speech therapy (mean = 4.89) to help speech correction.

**Table 2.** Mean and standard deviation (SD) of caregivers' needs

| Needs | Mean | SD |
|---|---|---|
| Nursing and Medical education management plan | | |
| 1) To know how to feed the infant | 3.44 | 1.24 |
| 2) To know how to do speech training | 4.89 | 0.33 |
| 3) To stimulate child development | 3.89 | 1.27 |
| 4) To know how to do home dental care | 4.33 | 0.50 |
| 5) To know how to prevent ear infection | 2.44 | 1.74 |
| 6) To know when to get a hearing test & audiometry | 3.11 | 1.69 |
| 7) To know how to communicate to the child what is happening to him/her | 3.11 | 1.69 |
| 8) To know what coping skills to teach when he/she is teased or bullied | 2.00 | 1.50 |
| Average | 3.63 | 0.55 |
| Service | | |
| 9) Where to get health services? | 3.67 | 1.32 |
| 10) Need to share decisions regarding treatment | 3.44 | 1.24 |
| 11) Need a referral from their local health services | 3.78 | 0.97 |
| 12) To know about their health coverage | 2.44 | 1.59 |
| 13) How to get economic support? | 3.00 | 1.32 |
| Average | 3.43 | 0.18 |
| Satisfaction | | |
| 14) Your family is economically self-sufficient | 3.11 | 0.60 |
| 15) You cannot afford travelling expenses | 2.11 | 1.16 |
| 16) Your child is satisfied in him/herself | 3.33 | 1.22 |
| 17) You are worried about your child's health | 2.33 | 1.22 |
| 18) You are satisfied with your child's appearance | 3.00 | 1.00 |
| 19) Your child has behavioral problems | 1.22 | 0.44 |
| Average | 2.47 | 0.33 |

If their children have delayed speech therapy or long-term habitual speech defects, they might lose confidence and not attend school. This is supported by a previous study(23) that found children with CLP, who had hearing and speech problems, were afraid to attend school at the appropriate age. Most caregivers expected that their children should have normal speech characteristics like their peers. Therefore, speech therapy with a home program was one of the most important that caregivers wanted to know. Dental care at home was the second requirement caregivers needed to know. Children with CLP are prone to dental caries and malocclusion (Malocclusion Class III)(24) and necessitated long-term care(2,25). Home dental care was also one of the main demands. Health care professionals should provide the information for caregivers to help their children cope with dental problems.

With regard to coping skills when children are teased or bullied (mean = 2.00) (Table 2), the caregivers were not seriously concerned. This might result from Thai living style or the eastern living family, unlike the western family unit (nuclear model comprised of parents and their children), where the extended family, all members, live together in the same house, particularly in the country side. Family members were very supportive of each other and their siblings normally lived in the same village and schooled together. Therefore, peers or siblings, those who were familiar with children with CLP, were readily accepted. This agreed with QoL in Table 3 (item 9) that family members were very supportive (mean = 3.67). Therefore, caregivers were not much concerned about coping with teasing and bullying.

For medical services, most of caregivers obtained referral from their local health service to tertiary or secondary health care units (mean 3.78) to get good services and wanted to know where they could get health services for their children (mean = 3.67) (Table 3). These findings supported previous study(26), which examined interdisciplinary care on timing of CLP and revealed that family of the children with CLP needed to know about a health care unit they could access because most caregivers still lacked of understanding related to diseases and multidisciplinary approaches. Consideration of expenses, caregivers had minor concern about medical costs and expenses because

**Table 3.** The participating caregivers' quality of life based on the Thai cleft QoL

| Items | Mean | SD |
|---|---|---|
| 1) You have to work more to cover CLP health expenses | 2.44 | 1.42 |
| 2) You quit your job or work to care for the CLP child | 2.11 | 0.93 |
| 3) You have to borrow money | 1.56 | 1.01 |
| 4) You have no enough time to work because you spend so much time on CLP care | 2.33 | 1.12 |
| 5) Your family has no leisure activity because you have to do much on CLP child care | 1.89 | 1.27 |
| 6) Your family has little happiness because of the CLP child | 1.78 | 0.97 |
| 7) You have less time to care for your other children | 2.00 | 1.12 |
| 8) You lack energy because of the CLP child care | 1.56 | 0.73 |
| 9) Your family is supportive | 3.67 | 1.32 |
| 10) You are afraid to get pregnant again | 2.00 | 1.32 |
| 11) You worry about your CLP child's future | 2.78 | 1.48 |
| 12) You pity the CLP child | 1.56 | 0.73 |
| 13) Your family is resolved to find solutions to problems | 3.33 | 1.22 |
| 14) Your family has been strengthened | 3.22 | 1.20 |
| 15) The CLP child is disliked by his/her other siblings | 1.56 | 1.33 |
| 16) The CLP child has more temper tantrums | 1.11 | 0.33 |
| 17) The CLP child's illness has given your health problems | 1.56 | 1.01 |
| 18) You have less time to care for yourself | 1.22 | 0.44 |
| 19) You have less time to rest | 1.56 | 1.01 |
| 20) You have decreased sexual enjoyment | 1.44 | 0.73 |

SD = standard deviation

there is universal coverage for health care in Thailand(27); however, transportation and living expenses remained the burden for family because the children had many medical services and appointments from multidisciplinary approaches.

The present study showed that caregivers were satisfied that children with CLP got surgery on time and had normal or near normal development which is consistent with Augsornwan et al(28). Moreover, QoL in this article supported Tawanchai Cleft Center's study of quality of life outcomes(29) that found the children with CLP had the highest psychological quality compared to other aspects. The caregivers of the children with CLP had economic challenges as their top concern was due to the fact that these birth defects needed long-term commitments for treatment and follow-up(3). They deserved compensation for living and expenses for such long duration from birth to teenager or adulthood. Foundation or Non-Profit Organization (NGO), Thai Red Cross, Tawanchai Foundation etc., should provide support to stabilize their financial woes arising from prolonged management protocol.

This present study is the pioneer study that highlighted caregivers' role and needs for the children with CLP. This might initiate health care providers' awareness for providing information and treatment for them. However, it is a preliminary study with some limitations e.g., a small sample size from a local mobile speech camp, Chiang Kham Hospital, Phayao, where speech services were not available. The interview process may have been affected by the caregiver's stress during the camping and being under staffed in helping caregivers whilst camping. A large sample sized study in future with adequate staffing and recreational activities for accompanying children may provide better results.

## Conclusion

The needs of information for the majority of the caregivers included treatment, development, particularly speech services, and general health, respectively. Mother plays a major role in taking care of the children with CLP. This was useful information in planning future support for the needs of the caregivers for the children with CLP.

## What is already known on this topic?

Children with CLP face many challenges, including physical, psychological, and economical problems which need multidisciplinary approaches and long-term treatments. Parents and caregivers, particularly who live in the rural and remote parts of the country are far from tertiary centers with multidisciplinary approaches, need to seek knowledge or treatment information and have compensatory mechanism to coping these problems including QoL.

## What this study adds?

Mother plays the major role in taking care for the children with CLP. Most caregivers firstly searched for information regarding medical treatment, followed by the program and planning for speech therapy and development promotion to support their children to have normal development. They had high psychological quality; however, they were still concerned about economic problems from long-term treatment. Health care providers should prepare information with regard to the caregivers' needs in order to support the children with CLP and their family, particularly in medical treatment, speech therapy and economic promotion.

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## Potential conflicts of interest

None.

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## *บทบาทของผู้เลี้ยงดูหลักในการดูแลเด็กปากแหว่งเพดานโหว่ในค่ายฝึกพูดเคลื่อนที่*

***อุษา โถหินัง, เบญจมาศ พระธานี***

*ปากแหว่งเพดานโหว่เป็นความพิการของปากและใบหน้าแต่กำเนิดที่พบบ่อย การดูแลรักษาต้องใช้ระยะเวลายาวนาน (ตั้งแต่แรกเกิด-วัยรุ่น) และต้องการการดูแลรักษาจากทีมสหสาขาวิชาชีพ ปากแหว่ง เพดานโหว่ มีผลต่อสุขภาพทางร่างกายและจิตใจของเด็กอีกทั้งยังเป็นภาระต่อผู้เลี้ยงดูหลัก เด็กที่มีภาวะปากแหว่งเพดานโหว่มีปัญหาหลายด้านเช่นโครงสร้างของใบหน้าผิดปกติกลืนลำบาก ปัญหาภาษาและการพูดปัญหาการได้ยิน ฟันผิดปกติ พ่อแม่หรือผู้เลี้ยงดูหลักเป็นผู้มีบทบาทสำคัญในการเลี้ยงดูเด็ก*

***วัตถุประสงค์:*** *เพื่อศึกษาถึงบทบาทของผู้เลี้ยงดูหลักในการดูแลเด็กปากแหว่งเพดานโหว่ที่มาเข้าค่ายฝึกพูดเคลื่อนที่ ที่โรงพยาบาลเชียงคำ จังหวัดพะเยา ประเทศไทย การศึกษาครั้งนี้เป็นการงานวิจัยเชิงคุณภาพ ผู้เลี้ยงดูหลักของเด็กปากแหว่งเพดานโหว่ที่มาเข้าค่ายฝึกพูดเคลื่อนที่ที่โรงพยาบาลเชียงคำ จังหวัดพะเยา เป็นกลุ่มตัวอย่างในการศึกษาเก็บข้อมูลโดยใช้แบบทดสอบสอบคุณภาพชีวิตของศูนย์ตะวันฉาย แบบวัดคุณภาพชีวิตของเด็กปากแหว่งเพดานโหว่ฉบับภาษาไทย (Tawanchai Quality of Life and Thai cleft Quality of Life Questionnaires) และการสัมภาษณ์เชิงลึก ทำการวิเคราะห์โดยใช้ Leonard Method*

***ผลการศึกษา:*** *พบว่ามารดาเป็นผู้เลี้ยงหลักในการดูแลเด็กปากแหว่างเพดานโหว่ ส่วนใหญ่มีอาชีพเกษตรกรรม สิ่งที่ผู้เลี้ยงหลักแสวงหาความต้องการเรียงตามลำดับดังนี้ 1) การรักษา (70.40%): ข้อมูลที่ต้องการมากที่สุดคือข้อมูลที่เกี่ยวกับการรักษา 2) การส่งเสริมพัฒนาการ (70.20%), โดยเฉพาะด้านภาษาและการพูด 3) การดูแลรักษาทั่วไป (52.60%): โดยเฉพาะด้านการป้องกันการติดเชื้อของทางเดินหายใจและการมีน้ำในหู รวมทั้งการทำอย่างไรที่จะทำให้เด็กมีการดื่ม กินอาหาร ดูดกลืนอาหารได้อย่างมีประสิทธิภาพและการได้รับอาหารที่ดีตามลำดับ*

***สรุป:*** *มารดาเป็นผู้เลี้ยงหลักในการดูแลเด็กปากแหว่างเพดานโหว่ ปัญหาในการดูแลเด็กปากแหว่งเพดานโหว่ที่ผู้เลี้ยงหลักต้องการทราบมากที่สุด คือการรักษาตามด้วยการกระตุ้นพัฒนาการด้านต่าง ๆ โดยเฉพาะด้านการบริการด้านการแก้ไขการพูด ข้อมูลที่ได้เป็นประโยชน์ในการวางแผนการรักษาและให้คำแนะนำสำหรับผู้เลี้ยงหลักรายใหม่ต่อไป*

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